

## Guide to Chapter 7

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## CHAPTER 7

# Consumer-Directed Home and Community Services<sup>1</sup>

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*Individuals with disabilities want and expect to control their own lives. This includes having a direct say about the home and community services and supports they receive through the Medicaid program. Increasingly, states are implementing consumer-directed models of home and community service delivery that provide options for individuals and their families to direct and manage their own services and supports. Consumer-directed services are an alternative to traditional agency-based service delivery models and can be offered alongside traditional models. This chapter describes the main features of consumer-directed home and community services, and the interplay between consumer-directed options and Medicaid policy. It focuses on services furnished through the Medicaid personal care services state plan benefit and the 1915(c) HCBS waiver authority. The chapter includes examples of several states' consumer-directed models.*

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### Introduction

Home and community service programs are frequently criticized for operating under a so-called *medical* or *professionally managed model*, under which professionals decide what services will be provided and how, when, and by whom. Many individuals feel these models do not meet their needs. Consumer-directed (CD) services first emerged in personal assistance services as an alternative to the individual's being limited to obtaining attendant services only from employees of professional agencies or from specific agencies licensed, certified, or otherwise authorized under a public program. A CD service model: (a) gives beneficiaries (and/or their families) the authority to develop service and support plans that reflect their wishes and preferences, and (b) gives them the choice of hiring/firing, scheduling, training, supervising, and purchasing services and, within the boundaries established by law, directing the payment of personal assistance workers and other service and support providers.<sup>2</sup>

Since its inception, the Medicaid program has been premised on the statutory principle that each beneficiary of service has the right to choose his or her own health care provider.<sup>3</sup> Over the past few years, as Medicaid's role in furnishing home and community long-term services has expanded, consumer direction and self-management of services have emerged as critical elements in enabling people with all types of disabilities to direct and manage their own services and supports. CD models are being increasingly used in the provision of Medicaid home and community long-term services. And state-initiated approaches, aimed at increasing the individual's choice and control with respect to Medicaid services and supports, continue to generate much interest throughout the country. These approaches include the Self-Determination for People with Developmental Disabilities, Cash and Counseling, and Independent Choices initiatives.

### Personal Assistance Service Delivery Models: Two Ends of a Continuum

Two examples of state personal assistance service delivery models illustrate the ends of a continuum, with many different models falling between them.

#### Consumer-Directed Personal Assistance Service Delivery Models

Consumer-directed (CD) models enable individuals to hire and fire, schedule, train, and supervise their own personal assistance providers (usually termed aides, attendants, or workers), with few restrictions on who can be hired. A CD model typically puts all responsibility for recruiting and selecting an aide on the individual (or family) and usually assigns the individual responsibility for ensuring that the aide(s) know how to do the work and for training the worker(s) if necessary. Public programs occasionally assist in identifying potential candidates, by providing a worker registry or helping the consumer perform a criminal background check. A CD model may also make publicly funded consumer and worker training available. Although the number of hours of personal assistance authorized for the individual in any particular month might be limited, individuals have the authority to schedule when the assistance will be provided, and both consumer and worker are free to negotiate schedule changes. A full-fledged CD model also involves individuals in the process of paying their workers (e.g., by signing timesheets), even though the actual wages are paid from public funds.

#### Professionally Managed Service Delivery Models

Professionally managed models require that aides be employees of authorized home health or home care agencies. Agencies hire workers according to agency criteria and assign employees to serve particular consumers. Choice among agencies is limited by the number of authorized providers in the area where the consumer lives. Frequently, there is only one such agency. Consumer choice of agency aides is generally restricted to “veto” power—although dissatisfied consumers may ask to have a worker replaced, and the agency will generally honor such a request as long as another worker is available. Agencies may shift employees from one individual to another—although they typically try to honor individuals’ requests to have the same workers on a regular basis. Agencies also schedule the aides’ work hours and may determine whether or to what extent they will accommodate consumer scheduling preferences. Agencies also conduct aide training and supervision. Some public programs mandate minimum training and supervision requirements. Others leave it up to the agencies or state licensing laws to set such requirements. Since training, certification, and professional supervision requirements can affect service costs, the added value of such requirements needs to be carefully assessed.

This evolving concept, referred to alternatively as self-determination, consumer-directed services, and participant-driven supports, is having a significant impact on the development and implementation of home and community services and supports for people with developmental disabilities, physical disabilities, and serious mental illness, as well as elderly individuals who have all types of disabilities. Regardless of the nomenclature used, implementing the concepts of consumer direction or self determination enables states to offer individuals the opportunity, support, and authority to direct the services they receive.

The principles of consumer direction encompass the goal of affording consumers the authority and tools to craft their own services plans, with the freedom to use both traditional and nontradition-

al providers and to direct and manage their services and supports. In the CD model, the Medicaid beneficiary is his or her own “care/service manager” (with the assistance, at the discretion of the individual, of friends and family members). Individuals still have access to advice and professional expertise. However, this assistance takes the form of educating and supporting consumers to do their own care planning and service coordination, rather than doing such tasks for them.<sup>4</sup>

Assistance for individuals in managing and directing their home and community services and supports can be provided by paid professionals who are variously termed *service coordinators*, *support brokers*, *personal agents*, *counselors*, or *consultants*. This new terminology underscores the philosophical differences between professional case/

care management as typically practiced and supporting individuals in directing and managing their own services.<sup>5</sup>

The principles of CD services are also reshaping the provision of home and community services for individuals with cognitive disabilities. For example, *self-determination* for people with developmental disabilities embraces the principle that individuals should have the authority to select, direct, and manage their services. In self-determination, individuals may enlist and invite friends and family members (in the form of a “circle of support”) to assist them in directing and managing services. The person’s legal representative or a surrogate decision maker may also assist and advise the individual and perform some service management tasks.

Until recently, CD models have been seen as appropriate mainly for younger adults with physical disabilities, because these models originated in the independent living movement initiated by this group. However, research suggests that consumers of all ages and their families would like to be more actively involved in planning and directing the services they receive.<sup>6</sup> Not surprisingly, state policymakers, program administrators, and consumer constituency groups are increasingly recognizing CD principles as having broad applicability across the full spectrum of individuals who need home and community services, including elderly persons and persons with cognitive disabilities (e.g., persons who have a severe mental illness, a developmental disability, or dementia). CD service models are seen as an important means to improve consumer satisfaction with services, involve individuals and families in improving the quality of services, and promote cost-effective service delivery.

Limits on the permissible scope of consumer direction are necessary, of course, when services are financed with public funds. In many CD service models, limitations on consumer choice and control are delineated—with a clear distinction between the gate-keeping and monitoring functions necessary to maintain fiscal control and public accountability, on the one hand, and the CD features of the model, on the other.

It is also important to note that CD models can (and usually do) operate side by side with professionally managed service delivery models. Individuals and families differ in the extent to which they wish to take on full management of their services. Some people want to exercise a high level of control, while others prefer to have services and supports managed by a provider agency—so long as the agency is responsive to their needs and preferences. Consequently, neither individuals nor states face an *either/or* proposition. What is important is that home and community services afford a full range of options for consumer direction.

There is little doubt that CD service principles will fundamentally reshape the future provision of home and community services for people with all types of disabilities.

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## Consumer Direction and Medicaid

As the role of the Medicaid program in underwriting home and community services has expanded, questions have arisen concerning the compatibility of CD models and principles with Medicaid requirements. Part of the mythology that surrounds the Medicaid program is that Federal rules dictate the use of a medical or professionally directed model and that, therefore, the program cannot accommodate or might actually be hostile to CD models in the home and community services arena. This is not the case.

For example, Medicaid can cover long-term services provided by in-home aides or attendants in three ways—under the mandatory home health state plan benefit, the personal care services optional state plan benefit, and 1915(c) home and community-based services waiver programs. Of these, only coverage under the mandatory home health benefit limits the provision of services to Medicare/Medicaid certified home health agencies that meet Federal “conditions of participation”—conditions that limit the extent to which individuals can direct their own services. Only a few states (e.g., Colorado, Delaware) finance even a small amount of long-term home attendant care under the home health benefit. In no state, however, is the home health benefit the only or even

the primary mechanism for financing personal assistance services. Most states offer Medicaid personal assistance services either through the personal care services optional state plan benefit and/or under one or more 1915(c) waivers. Neither of these financing mechanisms requires states to adopt a medical or professional model of service delivery.

CD models for personal assistance services first took hold in various state non-Medicaid personal assistance programs, most notably the California In-Home Supportive Services (IHSS) program. These programs grew out of the independent living movement for people with disabilities during the 1960s and 1970s. Since then, and at a quickening pace in recent years, the essential features of CD services have been incorporated in many Medicaid home and community service programs:

- Although many states require that personal care services be provided by state licensed home care agencies (though not necessarily by Medicare/Medicaid certified home health agencies), other states allow CD organizations, such as independent living centers, to be personal care services providers. Many states also make it possible for beneficiaries to hire “individual providers” of attendant services, either directly or through CD provider organizations.
- Several states (most notably Oklahoma and Michigan) have covered Medicaid services provided by consumer-hired attendants under the personal care services optional state plan benefit for more than 20 years.
- New York’s personal care attendant program, which began in the mid-1970s, relied exclusively on consumer-hired attendants for the first several years. It then shifted to a model in which the great majority of personal care services were provided by licensed home care agencies. Since 1995, however, New York state law has required that all local Social Services Districts (which serve as the local administrators for the Medicaid personal care attendant program) provide a CD service option to any Medicaid consumer of attendant care who wishes to self-direct.
- Medicaid-funded CD personal attendant services are available on a very large scale in California, where the IHSS program serves close to 200,000 consumers annually, including 135,000 Medicaid-eligible consumers whose services are funded via the Medicaid personal care services optional state plan benefit. Over 90 percent of IHSS consumers receive attendant care from aides whom they hire directly. Use of Medicaid funding to cover personal attendant services provided to Medicaid-eligible IHSS consumers began in 1994.<sup>7</sup>
- In providing services for people with developmental disabilities, several states (e.g., Minnesota, New Hampshire, New York, Utah, and Wisconsin among others) have successfully modified their HCBS waiver programs to add CD service options as part of broader initiatives to promote self-determination.

A recent study found that half of the personal care optional state plan benefit programs in 26 states and 60 percent of the HCBS waiver programs in 45 states provided for CD personal care attendants.<sup>8</sup> In several states, one of the conditions imposed on people receiving Medicaid personal care services is that the individual (or a family member/surrogate) be capable of directing and supervising his or her support workers.

The fact that CD principles have already been embraced by many states in provision of Medicaid home and community services furnishes the most direct evidence that Federal policy does not dictate the exclusive use of professionally directed service delivery models.

In May 1996, HHS Secretary Donna Shalala reaffirmed the department’s support for home and community services and the principle of “offering consumers the maximum amount of choice, control, and flexibility in how those services are organized and delivered.”<sup>9</sup> The Secretary listed a number of specific principles HHS supported, including several focusing on consumer direction:

- Promoting greater control for consumers to select, manage, and direct their own personal attendant services

## CD Services for People with Developmental Disabilities

**Self-determination** is the ability of individuals to make the choices that allow them to exercise control over their own lives, to achieve the goals to which they aspire and to acquire the skills and resources necessary to participate fully and meaningfully in society (Oregon Institute on Disability and Development).

CD services for people with developmental disabilities are taking hold as an outgrowth of the self-determination movement.<sup>10</sup> Self-determination features the use of person-centered planning and individual budgets as tools that enable individuals to identify and direct their own services. Self-determination has also adopted some of the mechanisms (e.g., use of intermediaries) that were pioneered in CD personal assistance programs.

Individuals with developmental disabilities who participate in HCBS waiver programs frequently receive additional discrete services and supports (e.g., employment supports and habilitation) as well as personal assistance. Thus, CD models for people with developmental disabilities (in contrast to CD personal assistance models) often span multiple services.

Beginning almost two decades ago, many states clearly established that they would use person-centered planning methods in identifying which supports would be offered to meet the needs of waiver program participants. Wisconsin's HCBS waiver program for people with developmental disabilities has used person-centered planning to develop waiver plans of care since the program began in 1984.

In contrast to more traditional approaches, person-centered planning emphasizes individuals' expression of their life goals and the crafting of strategies to achieve these goals with a combination of paid and unpaid supports. In person-centered planning, the individual (along with other persons the individual chooses to invite to assist in developing the plan) is in charge of the support planning process. Several states (e.g., Michigan, Hawaii, and California) have changed their laws and policies to embrace person-centered planning as their principal tool in developing support strategies for people with developmental disabilities.

- Experimenting with alternative ways to pay for services (e.g., vouchers and direct cash payments) in addition to the traditional methods
- Encouraging use of alternative providers, including informal providers such as friends and relatives
- Developing new ways to help consumers train and manage their attendants.

In 1999, HCFA revised its guidelines concerning provision of personal care services under the Medicaid state plan, to clearly establish that states may employ CD models to provide these services. Section 4480 of the State Medicaid Manual states:

“A State may employ a consumer-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid benefici-

ary may hire their own provider, train the provider according to personal preferences, supervise and direct the provision of personal care services and, if necessary, fire the provider. The state Medicaid Agency maintains responsibility for ensuring the provider meets state provider qualifications...and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the state may either provide personal care services without consumer direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving services.” (See Appendix II for the complete text of this guidance.)

While these guidelines are specific to personal care/personal assistance services furnished as a Medicaid state plan benefit, they apply equally to similar services and supports that states furnish through HCBS waiver programs (under which states in any case have the latitude to offer services on a less restrictive basis than under their state

plans). The importance of these HCFA guidelines is that they clearly sanction the CD philosophy that has been in operation at the state level for many years—arrangements that also enable family members and other individuals to direct services (when the individual might not be able to do so by virtue of cognitive impairment, illness, or another reason).

While HCFA sanctions and supports CD models, Medicaid policy is still evolving to accommodate the principles (and some of the operating features) of CD service models. CD models depart from traditional Medicaid service delivery practices, featuring use of alternative administrative mechanisms and altering program/provider/beneficiary relationships. The basic framework of existing Medicaid policy is the product of a much earlier era. As such, it did not anticipate service models in which the consumer exercises considerable control. HCFA is taking several steps to clarify and update its program guidelines to accommodate CD service models, and has been working with states interested in offering CD services. Federal Medicaid policy poses certain issues with respect to the feasibility of operating some types of CD models (e.g., models based on “cashing out” Medicaid benefits). But it does not stand in opposition to CD models.

Several topics related to the interplay between Medicaid policy and CD services merit extended discussion, because they are often a source of uncertainty concerning the feasibility of furnishing Medicaid home and community services in a fashion consistent and compatible with CD principles. These topics include (a) service planning and authorization; (b) furnishing assistance to individuals in directing and managing their supports; (c) consumer choice and provider qualifications; and (d) performance of skilled nursing tasks. Each is discussed in turn.

## Service Planning and Authorization

CD service models depart from professionally directed service models by affirming that the individual plays a very active and decisive role in service planning. Planning goals are identified in collaboration with the individual and specify in

detail the services the person will receive. While person-centered planning methods have been associated mainly with services for persons with developmental disabilities, they are employed in home and community services for individuals with other disabilities as well.

With the exception of home health services, Medicaid policy does not dictate that home and community service plans must be prepared by medical, clinical, or case management professionals. Whether for HCB waiver services authorized in a plan of care or personal care/personal assistance services under the optional state plan benefit, states have considerable latitude with regard to empowering the individual to manage and direct authorized services. In personal assistance services, for example, many states already provide that individuals may directly schedule when authorized hours of services are to be furnished and alter the schedule to meet their needs. In an HCBS waiver program, states also may permit the individual to manage the schedule of service provision or alter the mix of authorized services to meet their changing needs without having to develop an entirely new plan of care. However, the statutory requirement that “services be provided pursuant to a written plan of care” must continue to be met. Specific provisions include the following:

**HCBS waiver program.** Federal law requires that the services individuals receive through an HCBS waiver program be provided pursuant to a plan of care.<sup>11</sup> Neither Federal law nor regulations specify the process by which this plan of care is developed. The plan of care must meet the requirements spelled out in the State Medicaid Manual<sup>12</sup> and any other requirements included in the state’s approved HCBS waiver request. The plan of care must also be consistent with the requirement that the state assure the health and welfare of the individual.<sup>13</sup> Person-centered or other alternative planning processes that yield a plan of care that meets these fundamental requirements are entirely acceptable with respect to the provision of HCB waiver services.

***Personal care/personal assistance services.***

At one time, Federal regulations dictated that optional state plan benefit personal care/personal assistance services be authorized by a physician and supervised by nursing personnel. In the Omnibus Reconciliation Act of 1993, states were specifically authorized to use alternative service authorization methods, including those that do not require the involvement of medical personnel.<sup>14</sup> This change enables states to adopt alternative approaches to service planning for this benefit.

### **Furnishing Assistance to Individuals in Managing and Directing Services**

Although CD service models are based on the individual's playing a direct role in identifying, arranging, managing, and directing his or her services and supports, a state may provide assistance to individuals in carrying out that role. Such assistance may include: (a) providing individuals with assistance, training, and education in supervising workers; (b) making the services of intermediary service organizations available (as described below); and (c) furnishing more intensive assistance in the form of "support brokers" or "personal agents."

With respect to intermediary services, a number of management activities may be considered necessary and reimbursable. These include assisting individuals with disabilities to manage workers who furnish services to them. Such activities are all part of a self-directed service delivery approach. Medicaid payment can be made for activities, furnished by an intermediary organization, that are set forth in an approved waiver, when they meet applicable Federal criteria.

HCFA is in the process of working with the states and other stakeholders to clarify the various payment options available to states to ensure fiscal accountability and the presence of an audit trail, and to ensure that these activities are supported and reimbursed in an appropriate manner. In CD personal assistance services and self-determination, consumer-selected intermediaries have emerged that provide a valuable service by assist-

ing the beneficiary with, or relieving him or her entirely of, some of the burdens that arise when the consumer performs employment-related tasks. The establishment and use of consumer-selected intermediary organizations support the direction and management of services by beneficiaries and also facilitate Medicaid program administration. States have the flexibility to structure provider agreements, and can define provider qualifications for self-directed services broadly, to support individual choice and direction.

With respect to the use of support brokers or personal agents, questions often arise concerning the interplay between this type of assistance and case management services, since Medicaid policy prohibits the provision of duplicate services to an individual. In particular, does furnishing one type of service preclude provision of the other service concurrently? So long as the assistance furnished to an individual to help manage his or her services is distinct from the activities a case manager performs on the individual's behalf, both types of services may be furnished to an individual. For example, in the Pennsylvania Person/Family-Directed Supports HCBS waiver program for persons with mental retardation, HCFA approved the state's offering "personal support" services (which include support broker/personal agent-like activities) based on the state's demonstration that such services were different from, and did not duplicate, the case management services also furnished to waiver participants.

### **Consumer Choice and Provider Qualifications**

The Medicaid "freedom of choice" principle establishes that individuals can select the provider(s) of the services for which they are eligible.<sup>15</sup> This principle applies to all Medicaid-funded services, including services furnished through HCBS waiver programs. The Social Security Act allows the Secretary to grant states a waiver of freedom of choice only in certain circumstances, and then only when other safeguards are in effect that preserve consumer choice.

Free choice of provider is absolutely necessary for individuals to be in the position of directing their

own supports. The Medicaid freedom of choice principle extends only to “qualified” providers, however. And therein lies the source of limitations and/or complications when seeking to implement CD service programs. Federal Medicaid policy (whether under the Medicaid state plan or through an HCBS waiver program) requires that a state spell out the qualifications required of providers and agree to contract only with providers who meet such qualifications.<sup>16</sup>

These qualifications must be reasonable (i.e., must relate to provision of the service), and they also must comport with state law. Within these stipulations, states have considerable latitude in establishing the qualifications required of providers of home and community services. The broader these requirements, the more people will qualify to provide services. Some states, however, limit provision of personal care services to entities that are licensed as “home care” or “home health agencies” or have been licensed to furnish community developmental disability services. This means, in turn, that individuals who provide home and community services and supports must be employees of such provider organizations. When provider qualifications are expressed in this fashion, they can pose barriers to promoting CD services. Some of these barriers arise from provisions of state Nurse Practice Acts, which frequently dictate that even non-health care related personal assistance be provided under the supervision of a nurse (and, not atypically, a nurse who him- or herself must be an employee of a licensed home care or home health agency).<sup>17</sup> (This topic is addressed in more detail below.)

Thus, a central task for states interested in promoting CD services is a thorough assessment of their provider qualifications to determine whether they need to broaden the types of organizations and individuals who may qualify as providers. It is not necessary to limit providers to traditional service agencies. Provider qualifications may be expressed solely with respect to the competencies and skills individual workers must possess. Many types of Medicaid HCB services may be furnished by friends, neighbors, and family members (other than spouses and parents of minor children). In various states (e.g., Kansas), families are encouraged to seek out individuals in their communities

who can provide some types of HCB services for people with developmental disabilities.

Consumer-directed models are choice-based models. The problem often is that the choices are too few (there may be only one or two “qualified agencies” that serve the area where the individual lives). Revamping provider qualifications can be vital not only in promoting CD services but also in expanding the potential sources of home and community services for people with disabilities more generally.

## Performance of Skilled Nursing Tasks

Although CD service models reject the medical model, avoiding it can be complicated by state laws and regulations concerning the performance of “skilled nursing tasks.” Federal Medicaid policy does not dictate who must perform skilled nursing tasks, merely that such tasks be performed in compliance with applicable state laws. But state laws and regulations often dictate that such tasks be performed by or closely supervised by a licensed nurse—thereby creating obstacles to CD service models with a seeming bias in favor of agency provision of services. Liability concerns sometimes also stand in the way of promoting CD service models.

To avoid duplicating home health benefits already available through Medicare or under the Medicaid state plan, many HCBS waiver programs do not offer skilled nursing or rehabilitative therapies. However, “skilled” paraprofessional services still may be provided by personal care attendants under HCBS waivers or under the personal care services optional state plan benefit—as long as the services are provided in conformity with the state’s Nurse Practice Act. A 1999 HCFA State Medicaid Manual transmittal specifically states:

“Services such as those delegated by nurses or physicians to personal care attendants may be provided so long as the delegation is in keeping with state law or regulation and the services fit within the personal care services benefit covered under a state’s plan. Services such as assistance

with medications would be allowed if they are permissible in states' Nurse Practice Acts, although states need to ensure that the personal care assistant is properly trained to provide medication administration and/or management.<sup>18</sup>

This policy and its applicability to optional state plan personal care services and HCBS waiver programs were reaffirmed in a July 2000 letter from HCFA to state Medicaid directors.<sup>19</sup>

Most states restrict performance of medical or "paramedical" tasks to licensed medical professionals, although most physician and nurse licensing laws do permit individuals to be trained to perform skilled services for themselves or for close family members. Federal Medicaid law references state licensing laws by requiring that state Medicaid plans comply with all "applicable" state and local statutes. Under the Nurse Practice Acts in most states, tasks such as catheterization, injections, and administering medications are considered invasive procedures, which may be performed only by paid personnel who are registered nurses or persons supervised by registered nurses.

Issues related to the performance of skilled nursing tasks stem from concerns about quality assurance and liability. Quality assurance is an important component of Medicaid home and community services but is beyond the scope of this Primer. The rest of this discussion focuses on liability issues.

In October 1997, the National Institute on Consumer-Directed Long-Term Care Services held a national conference to explore the pros and cons of various modifications to Nurse Practice Act statutes that relaxed restrictions on the performance of paraprofessional tasks by nonlicensed personnel.<sup>20</sup> One motivation for the conference was to find ways to reduce the very high costs of RN visits to the home—in some cases several times a day—without compromising the need for accountability. The conference focused on alternative approaches that had been implemented in several states. Two contrasting models emerged: *delegation* and *exemption*.

**Delegation.** Registered nurses (RNs) may delegate tasks considered within the scope of the nursing

profession to individuals they train and supervise. Accountability for delegated tasks remains with the RN. Some Nurse Practice Acts hold nurse delegators strictly accountable for any negative outcomes of tasks performed by their delegates. Tort law refers to this kind of liability as *vicarious liability*, derived primarily from the legal doctrine of *respondeat superior*, literally meaning "let the master answer." Under this doctrine, the nurse is held liable for any injury caused by the negligence or wrongdoing of his or her delegates. Other Nurse Practice Acts only hold the RN *directly liable* in a legal sense for the delegation process. Thus, if the worker to whom a task was delegated negligently harms the consumer, the RN would be liable only if it were established that his or her assessment, training, supervision, or other aspect of the *delegating process* were performed negligently.

Obviously, whether a state's Nurse Practice Act appears to hold a nurse delegator vicariously liable for negligence by the individual to whom tasks were delegated or only directly liable for the delegating process has major implications for whether or not nurses, as a practical matter, will be willing to delegate. (Most Nurse Practice Acts do not differentiate between delegation in an inpatient setting, such as a hospital or nursing home, as contrasted with nurse delegation in the home care setting.)

**Exemption.** The exemption alternative provides a way to deal with liability concerns. The primary difference between specific delegation and exemption is in where the authority and responsibility associated with each lie. In an exemption approach, it is the implicit right of the person needing a service to manage provision of a service, as he or she prefers, as long as the provider of service falls within the exempt category. Nurses are not held responsible for provision of the service. But they may continue to play an important role in educating the provider and the consumer of the service—as well as, in some instances, monitoring the service over time.

Several states have dealt with the delegation issue by providing specific "exemptions" in their Nurse Practice Acts for consumer-hired personal attendants in Medicaid-funded programs. (Most if not all states exempt family members.) This approach

not only protects nurses, who may assist in training consumer-hired aides without assuming liability for the aides' subsequent actions. It also has the advantage of clearly protecting the state against liability for any harm that might be caused by consumer-directed aides. The exemption provision in New York's Nurse Practice Act for consumer-hired attendants, for example, contains language specifically stating that the exemption applies to the Medicaid-funded CD personal care attendant program. Kansas also exempts its Medicaid HCBS waiver program, which serves self-directed persons with disabilities, from the provisions of its Nurse Practice Act. California users of personal assistance services are allowed to take responsibility for such tasks as long as a physician authorizes them to do so.

As Medicaid home and community services expand, states increasingly will need to grapple with the interplay between their Nurse Practice Acts and affording individuals opportunities to select community workers to perform some nursing tasks, particularly when such tasks need to be performed on a daily or more frequent basis. At the same time, states will also have to grapple with striking the right balance between safety and autonomy for clients in CD programs.

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## Endnotes

1. The primary contributors to this chapter are Gary Smith, Pamela Doty, and Janet O'Keeffe.
2. For a more detailed description of CD service models, see Doty, P., Benjamin, A.E., Matthias, R.E., and Franke, T. (1999). *In-home supportive services for the elderly and disabled: A comparison of client-directed and professional management models of service delivery—Non-technical summary report*. Washington, DC: Department of Health and Human Services.
3. Section 1902(a)(23) of the Social Security Act
4. In Kansas, peers (persons with disabilities) are the professional counselors for the beneficiaries served by the physical disability waiver program for persons under age 65.
5. Case management is not a preferred term in CD service models, although it is still used. See, for example, Cooper, R. (2000). From management to support: No more "business as usual." *Impact*, Vol.12(4). University of Minnesota: Institute on Community Integration, Research and Training Center on Community Living.
6. See, for example: Simon-Rusinowitz, L., Mahoney, K.J., Desmond, S.M., Shoop, D.M., Squillace, M.R., and Fay, R.A. (1997). Determining consumers' preference for a cash option: Arkansas telephone survey results. *Health Care Financing Review*, Vol.19(2), 73–96. Mahoney, K.J., Simon-Rusinowitz, L., Desmond, S.M., Shoop, D.M., Squillace, M.R., and Fay, R.A. (Winter 1998). Determining consumers' preferences for a cash option: New York telephone survey findings. *American Rehabilitation*, Vol.24(4), 24–36. Eustis, N.N., and Fischer, L.R. (1992). Common needs, different solutions? Younger and older home care clients. *Generations*, Vol.16, 17–23. Doty, P., Kasper, J., and Litvak, S. (1996). Consumer-directed models of personal care: Lessons from Medicaid. *Milbank Quarterly*, Vol.74(3), 377–409. Doty, P., Benjamin, A.E., Matthias, R.E., and Franke, T. (1999). *In-home supportive services for the elderly and disabled: A comparison of client-directed and professional management models of service delivery—non-technical summary report*. Washington, DC: Department of Health and Human Services.
7. For nearly two decades, IHSS was funded almost entirely with state dollars (with some Federal funding via the Social Services Block Grant). This was largely because of concerns that accessing Medicaid funds would impose a "medical model" on service delivery—in view of the Federal requirements that Medicaid-funded personal care services had to be "prescribed by a physician" and "supervised by a registered nurse." Congress eliminated these requirements effective October 1, 1994, although states may continue to apply them at their discretion. The Federal statute now specifies that personal care services may be authorized for an individual by either a physician in a plan of treatment, or in accordance with a service plan approved by the state.
8. LeBlanc, A., Tonner, C.M., and Harrington, C. (2000). *State Medicaid programs offering personal care services*. San Francisco: University of California.
9. The Secretary's statement also expressed the Department's commitment to researching innovations to promote greater consumer choice and control in home and community services, including research and demonstration projects "to find imaginative, new ways to maximize consumer choice and self-determination. Many of the elements of this research agenda will have the immediate result of helping many people receive the supports they need. We will, for example, look at new ways to help consumers hire, train and manage their attendants, at alternative providers and experiment with offering consumers cash instead of services."

Several of the research projects have since been completed and information on them may be obtained by visiting <http://aspe.hhs.gov/daltcp/home.htm>. Others (e.g., the Cash and Counseling Demonstration/Evaluation in Arkansas, New Jersey, and Florida that HHS is co-sponsoring with the Robert Wood Johnson Foundation) are ongoing. In addition, several new projects have been launched, most notably the HCBS Resource Network, which is jointly sponsored by ASPE, HCFA, and AAA (all in HHS). Although the overall goal of the network is to promote development and improvement of state home and community service systems, the network has a special emphasis on assisting states in designing CD approaches to financing and service delivery.

10. In many states, the shift to CD home and community services for people with developmental disabilities is being supported by grants and other technical assistance from the Robert Wood Johnson Foundation.

11. Section 1915 (c)(1) of the Social Security Act

12. 42 CFR 441.301(b)(1)(i), Section 4442.6

13. Section 1915(c)(2)(A) of the Social Security Act

14. Section 1905(a)(24) of the Social Security Act

15. Section 1902(a)(23) of the Social Security Act.

16. Section 1902(a)(23) of the Social Security Act.

17. This topic is addressed in Flanagan, S. A., and Green, P. (1997). *Consumer-directed personal assistance services: Key operational issues for state CD-PAS programs using intermediary service organizations*. Cambridge, MA: The MEDSTAT Group. The authors include an especially clear discussion of the steps that may be taken to address some of the problems and issues while still ensuring that the health care needs of individuals are properly addressed.

18. HCFA Medicaid Manual Transmittal Part 4, No. 73, September 17, 1999.

19. Olmstead Update Number 3. July 25, 2000. See Appendix II for the complete text of the letter.

20. The conference was a cooperative activity of the National Council on Aging and the World Institute on Disability, which was cosponsored by the Administration on Aging and the Office of the Assistant Secretary for Planning and Evaluation, U.S. DHHS.

**and community based services (HCBS): An assessment guide for states.** Washington, DC: Author. (85 pages)

This guide was developed to help policymakers, consumer advocates, and consumers look broadly at the array of HCBS available in their states and identify ways to make services more responsive to consumers' needs and preferences. Included are a discussion of consumer direction principles and practices; benchmarks; a self-assessment instrument; factsheets on key issues (e.g., Medicaid, nurse practice acts, fiscal intermediaries); and a list of resources for more detailed information. *A free copy of the draft guide—or just the set of factsheets—is available from NASUA, 1225 Eye Street, N.W., Suite 725, Washington, DC 20005, (202) 898-2578. The final guide, which will also include states' experience in assessing their programs, will be available from NASUA for a nominal charge early in 2001.*

**Flanagan, S., and Green, P. (October 1997). *Consumer-directed personal assistance services: Key operational issues for state CD-PAS programs using intermediary service organizations*. Prepared for the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE), Division of Aging and Long-Term Care Policy (DALTCP). Cambridge, MA: The MEDSTAT Group. (69 pages)**

This policy study identifies practices for intermediary service organizations to use when implementing consumer-directed personal assistance programs. The report is basically an "advice manual" intended for state program administrators. *This report, minus appendices, can be found on the Internet at [aspe.hhs.gov/daltcp/reports/cdpas.pdf](http://aspe.hhs.gov/daltcp/reports/cdpas.pdf). The full report and appendices may be ordered from the Office of Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201, fax (202) 401-7733, or via e-mail at [DALTCP2@osaspe.dhhs.gov](mailto:DALTCP2@osaspe.dhhs.gov).*

**Doty, P., Kasper, J., and Litvak, S. (1996). *Consumer-directed models of personal care: Lessons from Medicaid*. *The Milbank Quarterly* 74 (3): 377-409. (32 pages)**

This article compares various uses of the Medicaid personal care services (PCS) option for providing attendant services to people with disabilities who need assistance with daily living tasks. It uses descriptive data from a 1984 and 1985 World Institute on Disability survey, and subsequent in-depth case studies of six diverse state Medicaid PCS programs.

## Annotated Bibliography

**National Association of State Units on Aging (NASUA) (Draft, 1999). *Consumer direction in home***

**Flanagan, S. (April 1994). *Consumer-directed attendant services: How states address tax, legal and quality assurance issues*. Prepared for the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE), Division of Aging and Long-Term Care Policy (DALTCP). Cambridge, MA: The MEDSTAT Group. (71 pages)**

This study reviews 10 federal and state-funded consumer-directed attendant in-home care programs. Payment, employment-related taxes, quality assurance, and legal liability of CD programs are discussed. The authors suggest a model of consumer-directed care that incorporates the strongest features of the programs examined. *Order the full report from National Technical Information Service (NTIS), Department of Commerce, 5285 Port Royal Road, Springfield, VA 22161, or from the NTIS website, [www.ntis.gov](http://www.ntis.gov).*

